The experiences of AIDS orphans living in a township

Authors:
Dalena van Rooyen[1]
Sharron Frood[2]
Esmeralda Ricks[1]

Affiliations
[1]Department of Nursing Science, Nelson Mandela Metropolitan University, South Africa

[2]Gogo Trust, South Africa

Correspondence to:
Dalena van Rooyen

Email:
dalena.vanrooyen@nmmu.ac.za

Postal address:
PO Box 77000, Port Elizabeth
6013, South Africa

Dates:
Received: 28 June 2010
Accepted: 07 Nov. 2011
Published: 21 Feb. 2012

How to cite this article:
Van Rooyen, D., Frood, S. & Ricks, E., 2012, 'The experiences of AIDS orphans living in a township', *Health SA Gesondheid* 17(1), Art. #568, 11 pages. http://dx.doi.org/10.4102/hsag.v17i1.568

An overwhelming challenge to health-care professionals today, is the rendering of care services to AIDS orphans. This article is based on a study that explored and described the lived experiences of AIDS orphans in a township in order to understand their 'life world' as AIDS orphans. A further purpose was to provide information to primary health-care nurses (PHCNs), related professionals and partners involved in the care of these children, so that they could plan a care response to meet the orphans' unique needs. A qualitative research design that used an explorative, descriptive, contextual and phenomenological strategy of inquiry was employed. Data were collected by means of in-depth interviews from a purposively selected sample, and were analysed according to the steps of qualitative data analysis proposed by Tesch (Creswell 1994). Guba's model was used to ensure the trustworthiness of the qualitative data. Two main themes and their sub-themes were identified. The first theme was that children experience devastating changes in their life circumstances when they become AIDS orphans. The second theme highlighted how the participants rediscovered hope to persevere. Recommendations directed at nursing practice, education and research, were made based upon the findings.

'n Uitdaging wat professionele gesondheidswerkers huidiglik oorweldig, is dienslewering aan VIGS weeskinders. Die doel van die studie was om die geleefde ervaring van kinders wat in dorpsgebiede woon en VIGS weeskinders geword het, te verken en te beskryf ten einde hul leefwêreld te verstaan. Hierdie inligting kan deur Primêre Gesondheidsorg Verpleegkundiges (PVGs), verwante beroepslui en vennote betrokke by die versorging van hierdie kinders, gebruik word as basis om versorging te beplan wat in die kinders se unieke behoeftes sal voorsien. 'n Kwalitatiewe navorsingsontwerp met verkennende, beskrywende, kontekstuele en fenomologiese strategieë van ondersoek, is gebruik. Data is versamel deur middel van in-diepte onderhoude met 'n doelbewus geselekteerde steekproef. Data is geanaliseer ooreenkomstig die stappe van kwalitatiewe data analise volgens Tesch (in Creswell 1994). Guba se model was gebruik om die betroubaarheid van data te bepaal. Twee hooftemas en hul subtemas is geïdentifiseer. Die eerste tema was dat kinders dramatiese veranderinge in hulle lewensomstandighede ervaar wanneer hulle VIGS weeskinders word. Die tweede tema wat na vore gekom het, was hoe die deelnemers die hoop om voort te gaan met die lewe, herontdek het. Aanbevelings, gebaseer op die bevindinge, is gemaak wat verpleegpraktyk, onderrig en navorsing sal rig.

Introduction

Problem statement

'Acquired Immune Deficiency Syndrome (AIDS) has devastated the social and economic fabric of African societies and made orphans of a whole generation of children' (Matshalaga 2002). The term 'AIDS orphan' reported in the study, was defined as any child under the age of 18 years who had lost one or both parents through an HIV-related illness. According to the United Nations International Children's Funds (UNICEF) in 2006 an estimated 15.7 million children, that is 30% of the 53 million anticipated orphans from all causes in sub-Saharan Africa, will have lost at least one parent to AIDS by 2010. The joint United Nations' Programme on HIV and AIDS (UNAIDS) estimated in 2009 that there were 1.8 million AIDS orphans living in South Africa at the end of 2008. The statistics for AIDS orphans are calculated by using assumptions, such as the average number of children per mother, a reduction in fertility, and an increase in infant deaths caused by HIV-related illnesses. In 2007 alone, 30–36 million people were living with HIV worldwide, 2.2–3.2 million people became infected with the virus, and 1.8–2.3 million people died of HIV-related causes (UNAIDS 2008); therefore, many more children face orphanhood.

UNAIDS (2008) states that Africa is home to 77% of the world's 15 million orphans that resulted from HIV. Before the outbreak of AIDS, approximately 2% of all children in developing countries were orphans (Foster 2002). After AIDS became a pandemic, the estimated number of maternal, paternal and double orphans because of HIV-related causes in Malawi, South Africa and the Republic of Tanzania, rose from 1.2 million in 2001 to 2.9 million in 2007 (UNAIDS 2008). The startling reality of these figures hits home when one realises that 9 out of 10 children in sub-Saharan Africa would have lost both parents to HIV-related diseases by 2010.

In 2008, South Africa had the highest number globally of people infected with HIV, estimated at 5.3 million, which included 220 000 children under 15 years (UNAIDS 2009). This means that South Africa will ultimately have the highest number of orphaned children on the African continent. By 2010, 16% of all children in South Africa will be orphans. It was predicted (UNAIDS 2009) that more than 10% of those orphans would be AIDS orphans. In the Eastern Cape where this study was conducted, 35% of the population was HIV-positive and 22% of all AIDS orphans in South Africa were resident in the Eastern Cape (Jacobs, Shung-King & Smith 2005).

AIDS orphans in South Africa, as in other African countries, experience recurrent psychological trauma, which starts with the illness and death of their parents, followed by cycles of poverty, malnutrition, stigma, exploitation, sickness and often, sexual abuse (Guest 2001). The majority of orphaned children live in deeply impoverished households (UNAIDS 2009) and, therefore, there will be significant costs incurred in caring for these children in the long term. If no mechanisms are put in place, such costs will include an increase in the number of children who live on the streets, increased levels of juvenile delinquency, reduced literacy and, consequently, a huge economic burden will be placed upon the state.

Blanket statements about the role of the extended family in Africa as a safety net, and assumptions that relatives will be ready and able to assist orphans in need, should be treated with caution because, according to UNAIDS (2009), the extended family networks that have traditionally supported vulnerable members have been overstretched by the ravage caused by HIV-related diseases. AIDS eventually wears down the resources of the extended family and at the same time, the numbers of orphans are increasing. Children who are unfortunate enough to slip through the safety net of extended family support, are especially vulnerable to disease, malnutrition, illiteracy, exploitation, as well as the risk of HIV infection themselves. As the traditional family structures break down in the pandemic, the suffering of grandmothers and grandchildren increases as parents watch their children die and children watch their parents die (Guest 2001).

The researchers embarked upon the research reported here, cognisant of the fact that primary health-care nurses (PHCNs) are overwhelmed by the circumstances presented by AIDS orphans when attending clinics to access care. The aim of the study was to gain insight into the lived experiences of AIDS orphans living in a township in order to understand their 'life world' as AIDS orphans. Information obtained could be used as a basis when planning a care response to meet the unique needs of the orphans and could be disseminated to all participants by providing care to the orphans.

Research objectives

The research objectives were therefore:

- to explore and describe the lived experiences of AIDS orphans in a township
- to make information available about the lived experiences of AIDS orphans in a township to PHCNs involved in the care of AIDS orphans, so that they could use it as a basis in planning a care response to meet the orphans' unique needs.

In view of the above discussion, the following question was posed to guide this research study:

- How do children living as AIDS orphans in a township experience life?

This article will focus on the description of the research methodology utilised for the study, the discussion of the research results, and the conclusion and recommendations made.

Contribution to the field

The rationale for the study was to create an opportunity for AIDS orphans living in the townships to describe their impressions with regard to how they experience life. The information was used to create an understanding amongst healthcare professionals, particularly amongst professional nurses employed in primary health-care clinics, with regard to the needs of AIDS orphans so that appropriate care and support could be rendered to AIDS orphans.

Research method and design

Design

According to Burns and Grove (2009) qualitative research is a systematic, subjective approach used to describe life experiences and give them significance, and phenomenology is an approach that focuses on how life is experienced (Denscombe 2008). Exploratory studies, on the other hand, are designed to increase knowledge of the field of study, whilst descriptive research explains the phenomena being studied (Welman, Kruger & Mitchell 2010). The researcher, therefore, made use of a qualitative, exploratory, descriptive and contextual design with a phenomenological approach to inquiry, to explore and describe the lived experiences of AIDS orphans in a township. The research design selected, enabled the researcher to conduct an in-depth study, and to provide a thick description of the participants' real life experiences as it relates to living as AIDS orphans in a township. Human behaviour cannot be understood without appreciating the context in which it takes place (Welman *et al.* 2010); thus follows the reason for a contextual design. The demographics of the township communities where this research was conducted, is described in the following paragraph.

The three townships in which the study was undertaken are situated in the Nelson Mandela Bay, Eastern Cape Province. The total population of the three communities at the time of the study was approximately 112 369 people (Butler 2004). The communities in which this study was conducted were mainly Xhosa-speaking and from the lower socio-economic group. Poverty is rife in these areas. More than a third (38%) live in informal dwellings, such as shacks, whilst the rest of the population live in Redistribution and Development Programme (RDP) housing.

The research methods utilised for this research study are described in the paragraphs below.

Population and sampling

The research population for this study included all AIDS orphans aged 12–18 years residing in three identified townships in the Nelson Mandela Bay. A criterion-based purposive sampling strategy was used to select participants for this study. When using a purposive sampling technique, researchers rely on their experience, ingenuity and/or previous research findings to obtain a research sample deliberately in such a way that the sample may be regarded as representative of the relevant population (Welman *et al.* 2010). In order to participate in the research study, participants had to meet specific criteria. All the participants involved in this study were:

- either male or female and aged 12–18 years
- living in a township in the Nelson Mandela Bay
- orphaned as a result of a parent or loved one caring for them, who died as a result of an HIV-related illness
- orphaned for a minimum of 6 months (6 months was considered a suitable time period for the child to have experience of life as an AIDS orphan in a township)
- able to understand and converse in English.

Data collection methods

Data were collected through unstructured phenomenological in-depth interviews in this study, because the researcher intended to allow the participants to use their own words and develop their own thoughts. Allowing participants to ‘speak their minds’ is a good way of discovering detail about complex issues (Denscombe 2008). According to Jolley (2010) the interview enables a less structured, more flexible and in-depth gathering of data. In-depth interviews are usually employed in exploratory studies (Welman *et al.* 2010). The researcher conducted interviews with children living as AIDS orphans in a township to explore and describe their lived experiences to inform PHCNs, related professionals and partners, who provide care to AIDS orphans. All interviews were conducted in the privacy of the AIDS orphans’ homes. The opening question, *‘Can you tell me about your lived experiences of living as an orphan in a township?’* yielded spontaneous and rich descriptions of the phenomenon. The remainder of the interview proceeded by following up and exploring dimensions introduced in the stories told in response to the initial question posed.

Data gathering continued until the data reached saturation after eight interviews, which meant that the researcher was obtaining the same information from subsequent participants; therefore, there was little point in continuing with the data collection (Jolley 2010). Field notes provided a detailed record of all interviews, and enhanced the richness of the data gathered. Permission to use a tape recorder for the interviews was obtained from the participants prior to the interviews. Interviews were recorded with an audiotape and were transcribed verbatim to produce an accurate representation of the interview proceedings.

Data analysis

Data was analysed with Tesch’s method as described in Creswell (1994). The researcher first obtained a sense of the whole by selecting one document at a time to make sense of the data and then made short notes. Thereafter, topics were listed and clustered according to similarity. The most descriptive wording was found for the topics and categories were identified. Themes and sub-themes were then formulated. This method organises the data, creating a structure, which can then be analysed (Tesch, in Creswell 2003). Both the researcher and an independent coder undertook the process of coding the information to ensure the principle of trustworthiness.

A literature control was conducted by comparing the data with existing research, which allowed the findings of the research study to be contextualised within general scientific knowledge without any undue influence of that knowledge (Creswell 1994; Streubert & Carpenter 1995).

Ethical considerations

Ethical approval was obtained from the Nelson Mandela Metropolitan University’s Ethics Committee prior to conducting the research. The participants involved in this study had already been exposed to much harm by becoming and being AIDS orphans. The researcher was very aware of their vulnerability and the need for protection against further harm. The researcher strived to conduct this study in such a way that the ethical principles of no harm, confidentiality, privacy and anonymity were upheld (Polit & Hungler 1999).

All of the information about the aims of the study, including procedures of the study as well as the possible advantages of the study, was disclosed to the participants. All were informed about the reason for their inclusion in the study, the duration of the study and how the results would be published. The participants were offered the opportunity to consent or to decline to take part in the study and they were informed of their freedom to withdraw from the study at any time.

Trustworthiness

Trustworthiness was ensured via criteria of credibility, transferability, dependability and conformability. Babbie and Mouton (2002) indicated that, according to Lincoln and

Guba (1985), the key criterion or principle of good qualitative research is found in the notion of trustworthiness. Just as quantitative research cannot be considered as valid unless it is reliable, a qualitative study cannot be called transferable unless it is credible, and it cannot be deemed credible unless it is dependable.

The researcher responsible for the fieldwork ensured enhanced credibility through prolonged engagement with the participants, triangulation of data sources (interviewing different AIDS orphans), and peer debriefing. Peer debriefing was carried out with a similar status colleague, outside the context of the study, who has a general understanding of the nature of the study and with whom the researcher could review perceptions, insights and analyses (Babbie & Mouton 2002). To aid the possibility of transferring the findings, the researcher provided a dense description of both the purposive criterion-based sampling procedure and the research method and design employed in this research undertaking. The measures to ensure dependability included code-recoded procedures, dense descriptions of research methods, triangulation and peer examination. In this study, the research methodology was fully discussed. The researcher combined transcribed interviews, personal journals and research notes in the data collection process and a colleague, experienced in the field of research, carried out a peer review. Coding was carried out by an independent coder as well as by the researcher. Auditing by the supervisor and co-supervisor ensured that the research plan was evaluated repeatedly.The latter strategies enhanced confirmability.

Discussions of results

The research findings presented in this article resulted from the analysis of eight in-depth interviews conducted with AIDS orphans living in a township. All the participants informed the researcher that it was the first time that they had been asked to talk about their lives since they had become AIDS orphans. The participants shared deeply from their life experiences and expressed a desire for their stories to be told so that others in their situation would not feel alone.

The experiences of the AIDS orphans are presented in two themes with related sub-themes. The first theme identified was that children experienced devastating changes in their life circumstances when they become AIDS orphans. The participants were articulate in their responses to the changes they were experiencing and had experienced. They described the effect of the absence of their parent or loved one in the home, the high-risk behaviour they engaged in because of the devastation they experienced, and the feelings they were experiencing by becoming AIDS orphans. The second theme highlighted how the participants were rediscovering hope to carry on with life. The AIDS orphans in this study described how reliance on certain relationships caused hope to be re-established in their fragmented lives. They also identified engagement in certain activities such as education, belonging to community groups and engaging in community sporting activities, as enabling the restoration of hope in their lives. The two themes and related sub-themes are presented below.

Theme 1: Children experience devastating changes in their life circumstances when they become AIDS orphans

At a time in their lives when they should be cared for, the AIDS orphans found themselves abandoned by those who were supposed to embrace them. The burden of caring for AIDS orphans in existing family structures was too great for the family. Current extended family structures were already overburdened by poverty, unemployment and a decrease in numbers because family members afflicted with HIV-related illnesses subsequently die. There was no one to take these children in and care for them. They became bewildered, confused and hurt and found it difficult to describe the enormity of the devastation they experienced. They were overwhelmed and devastated by their experiences. The following stories testify of the devastation experienced by the children once they became AIDS orphans:

> 'Things in my home are different now that my mother has died. My grandmother was too old for us to take care of her. So she went to be with my aunt. I am sad about this because we did stay nicely with her after my mother died. So it's me and my cousin. We were afraid when this happened to us. No one came to help us or take care for us. We were worried about how we were going to get food and how would we survive. I was 13 years old when this happened to me. Since that time I take care of myself.' [Sharron Frood Interview with Participant 3, Nelson Mandela Bay, June 2006]

> 'All I can say is it's like I have a deep pain inside since I became an AIDS orphan I have no words to say how it feels. I have no one to go to help me. Sometimes I want to die.' (Sharron Frood Interview with Participant 1, New Brighton Township, May 2006)

Across the continent of Africa, AIDS has left in its wake many AIDS orphans who have to fend for themselves and who have to assume adult responsibilities at a young age. In South Africa, it has been stated that 'Orphans living in the township live on the edge of dreadful things. They are oppressed, poor, exploited, humiliated, ashamed and suffering because of the devastation they have come to experience daily' (De Boeck & Honwana 2005). In spite of this, they must somehow cope with the devastation they have experienced. When children lose their parents to HIV-related diseases, they do not only lose their parents but their childhood as well. The loss of childhood adds to the devastation of the parental loss, and this makes the orphans feel constantly overwhelmed by the devastation of their experience (Loening-Voysey 2002).

Sub-theme 1.1: The effects of the absence of a parent or a loved one in the home, on AIDS orphans

The death of the primary caregiver left a void in the lives of the AIDS orphans who participated in the study. Even the home became empty. One participant said:

> 'When my mother was alive and my brothers were at home I liked being at home with them. We used to help with the cooking and it was a lovely fun time. We just liked to be together. Now I don't like to be home. It's empty and a sad place to me now. It's like the life has gone from my home.' (Sharron Frood interview with participant 1, Nelson Mandela Bay, May 2006)

These children were affected even further by the death of a parent or a loved one because they had lost a caregiver and confidant:

> 'The thing that affects me the most is the loss of my mother's care. She was always encouraging me and sharing ideas with me. I miss those kind words of encouragement and hope. She was always patient and kind. I miss her meeting me from school.' (Sharron Frood interview with participant 2, Nelson mandela Bay, May 2006)
>
> 'Since my mother did pass away, no one listens to me like she did. I like to tell her about my problems now she is not here anymore. I miss her.' (Sharron Frood interview with participant 4, Nelson Mandela Bay, June 2006)

Another participant told the researcher that she was used to being spoiled on her birthday and at Christmas, but since her father had passed away these days have become 'nothing days':

> 'When my father was alive and it was my birthday he used to buy for me a cake and a present which was usually clothes. Now when it's my birthday, it's a nothing day. It's just like that. Father's day and Christmas are also like that to me now they are just nothing days.' (Sharron Frood interview with participant 3, Nelson Mandela Bay, June 2006)

The participants further stated that the death of a parent and loved one affected them in that they did not have food and clean clothes. They referred to this as:

> 'When I do come home from school there is no food. It was never like that before. When my mother was alive there was always food in the house.' and 'When my mother was alive I always had clean clothes. Now we don't always.' (Sharron Frood interview with participant 5, Nelson Mandela Bay, June 2006)

After the death of their parents or loved ones, the orphans all experienced an increased financial burden. They were often hungry because they were without money for food. One participant said:

> 'After the death of my mother I was left alone without any money. What can a person do without money? I can't buy clothes or pay school fees and I can't even buy food. This did distress me too much. Because I had no money I can't eat or wash my clothes. I feel humiliated because of this. One day I did go to school without shoes because I didn't have any. The children did laugh at me. I know my education is important so I went barefoot. Then a teacher from school did give shoes to me.' (Sharron Frood interview with participant 4, Nelson Mandela Bay, June 2006)

Other household needs also could not be met because of financial insufficiency. In one of the participant's homes were broken windows in his bedroom, and in another home, a hole in the ceiling. The children all replied to enquiries about these things in the same way: 'There is often not enough money for food so how can I buy other things that we need?' According to Wild:

> When a breadwinner of the family falls ill and dies, children who become orphans in a family incur severe loss. There is no inheritance whatsoever and they are often left destitute. Orphans frequently have insufficient food and often fall out of school to work in menial jobs to earn money to buy food, or worse they become prostitutes. (Wild 2001)

Sub-theme 1.2: AIDS orphans engage in high-risk behaviour to alleviate the effects of the devastation they experienced

It has been said, 'adversity can make a person strong but it will be an unusual AIDS orphan who gains any strength from the pandemic' (Guest 2001). The damage to AIDS orphans who grow up alone will be deep and permanent. The number of children living on the streets will increase and AIDS orphans will be 'forced into criminal activities, because they have nowhere else to turn for survival' (Guest 2001).

The participants confirmed the above statement by Guest that the AIDS orphans were engaged in high-risk activities such as criminal behaviour, prostitution and substance abuse to alleviate the effects of the devastation they were experiencing and as a means of survival. The following excerpts underscore this:

> 'After my mother died I struggled to get food and clothes. One day I steal washing from the washing line in a house far from mine. I stole the top because it was nice and giving me status in the community. I stole most of my clothes like this. One day I get caught. I did community service for 6 months. I had to do cleaning in the Empilweni TB hospital. It was too terrible. I don't steal anymore.' (Sharron Frood interview with participant 1, Nelson Mandela Bay, May 2006)
>
> 'I was a good boy when my grandmother was looking after us. When my relatives come and take her and all our furniture I was sad. I had no clothes and food. I did bad things. I used to wait in the street and rob people. I would beat them up and steal anything I could so I can survive. I am ashamed at what I did. I don't do it now because I get help through Sisonke Sophumelela (orphan care programme), now I am in school, I have uniform and clothes and enough food to eat.' [Sharron Frood interview with participant 3, Nelson Mandela Bay, June 2006]

Some of the female participants told the researcher that they turned to prostitution to provide for themselves, their siblings and an ill parent at home, but that they were ashamed of their behaviour:

> 'I am ashamed about what I am to tell you. We were six children and had no money for food. I was approached by two old men in the community to have sex with them. So I have sex with them without using a condom. With the money they give to me I buy food and clothes for me and my brothers and sisters. My brothers and sisters don't know what I do; they just know all the time I am getting money for food.' (Sharron Frood interview with participant 6, Nelson Mandela Bay, June 2006)
>
> 'I wish I didn't do this thing because I feel dirty inside. I didn't enjoy it because they were rough and they smell terrible. I had sex with them without a condom because then they do give me more money. I was afraid of HIV but I did have sex with them anyway. I didn't care. When I came home after I had sex with them, I was crying that my life is so low that I must do this. Then sometimes I am glad because I see my family is getting food and they are happy to have it and do love me. I love them too.' (Sharron Frood interview with participant 6, Nelson Mandela Bay, June 2006)

Guest (2001) is of the opinion that female AIDS orphans are particularly vulnerable to sexual abuse, primarily by older men who provide them with money for the necessities of daily living. Orphans are bewildered by their overwhelming circumstances and will turn to prostitution and succumb to high-risk sexual practices, such as unprotected sex, to earn money to meet the basic needs of their family (Foster 1998; Loening-Voysey 2002, in Mogotlane *et al.* 2010).

Some of the participants shared that they have engaged in substance abuse to deal with their loss and to cope with the feelings they experienced because of the loss:

> 'After the death of my mother I hang out on the street with my friends. They give me dagga to smoke. I like it because it makes the burning anger in me to go down and I feel peaceful.' (Sharron Frood interview with participant 1, Nelson Mandela Bay, May 2006)
>
> 'I drink to forget. I like to be with my friends and drink and laugh and be free. I like it better than smoking dagga because when the dagga wears off you get too hungry. Alcohol is not like that. It's better when I go and I do drink with my friends it's like a family. We do trust each other and laugh.' (Sharron Frood interview with participant 6, Nelson Mandela Bay, June 2006)

Meyer (2005) confirms that the participants turn to substances of abuse in order to deal with the death of a parent or loved one, and to cope and deal with the feelings and emotional reactions resulting from this loss in the following statement:

> Abuse, rejection, betrayal, disappointment, judgement, criticism and grief all cause pain in our lives. It has been stated that emotional pain is often more devastating than physical pain. Medication can alleviate physical pain, but emotional pain is not easy to deal with. When pain and discomfort become more than people can withstand they turn to a substance to alleviate the pain they feel. (Meyer 2005)

Guest (2001) is of the opinion that children in emotional distress will often withdraw and isolate themselves and they will try to numb the pain by smoking dagga, drinking alcohol or sniffing glue. These measures expose AIDS orphans to greater risk and often leave them to suffer the consequences of anti-social behaviour, in which they can engage when drugged by these substances.

Sub-theme 1.3: Feelings experienced by participants as a consequence of becoming AIDS orphans

The participants reported both positive and negative feelings at becoming AIDS orphans because of the death of a parent and/or a loved one, with negative feelings predominating. They were at times very articulate and willing to describe the feelings associated with their experiences, and clearly expressed the feelings and emotions they experienced on becoming AIDS orphans. One such description was:

> 'I feel like I have a pain deep in my chest. If I could take hold of it and pull it out it would be much better. But nothing does take that pain away since my mother did die. Even when I cry it is still there, sometimes it burns in my chest.' (Sharron Frood interview with participant 7, Nelson Mandela Bay, July 2006)

According to Ivey (1999), feelings or emotional reactions can be categorised under four basic word groups, namely feelings that makes one **sad, mad, scared** and **glad**. This categorisation will be used to group the feelings and emotions expressed by the participants in becoming AIDS orphans. The feelings and emotions experienced by the AIDS orphans in this study have been tabulated into these four word groups (Table 1).

The following discussion will present the findings according to the four word groups, beginning with those of the '**sad**' group in which feelings of distress, helplessness, abandonment, loneliness, feeling grief-stricken and neglected, were expressed by the AIDS orphans.

Some of the participants experienced feelings of **distress** as the following quotation illustrates**:**

> 'When my uncle die [sic] I went to see him. When I see his body it was covered in worms and this did distress me much. I was suffering by what I saw I couldn't sleep I was just seeing in my mind his body covered in worms.' **(**Sharron Frood interview participant 3, Nelson Mandela Bay, June 2006)

AIDS orphans are burdened by too many responsibilities at a young age. They feel **helpless** and **afraid** because they have been prepared inadequately to cope with these responsibilities (Foster 1997):

> 'I looked all around for help but there was no one to help because everyone was also suffering. They are alone like me without help and afraid. Most days after the death of my parents I just didn't know what to do.' (Sharron Frood interview with participant 6, Nelson Mandela Bay, June 2006)

The following statement made by the participants, testify to the fact that they have experienced feelings of **abandonment**:

> 'One day I was taken care of. The next day I was left without any food. It was like that I was just abandoned. There was no one to take care of me. I was alone.' (Sharron Frood interview with participant 7 Nelson Mandela Bay, July 2006)

The AIDS orphans in this research study all expressed feelings of **loneliness** because of the loss of a parent or loved one, rejection by family members, and because of the ridicule they faced at school and in the community by friends:

> 'My home is lonely now my mother has died. When I come home from school there is no one there. I am just alone. It is like that now. I feel lonely because of this.' (Sharron Frood interview with participant 5, Nelson Mandela Bay, June 2006)

The participants expressed **grief** as long bouts of crying and deep pain associated with the sense of loss they experienced. They articulated it as follows:

> 'All I can say is that when my grandmother died it was too much to me. She was too good to me after the death of my mother and I did love her too much. She pass [sic] away and I feel like I did die inside my heart.' (Sharron Frood interview with participant 8 Nelson Mandela Bay, July 2006)

TABLE 1: Feelings experienced by the AIDS orphans in the four word groups.

Sad	Mad	Scared	Glad
Distressed	Angry	Overwhelmed	Glad
Helpless	Rejected	Fearful	Joyful
Abandoned	-	Uncertain	Loved
Lonely	-	Suicidal	Hopeful
Grief-stricken	-	-	-
Neglected	-	-	-

Source: Authors' original data

> 'For a long time after my mother died I just cried and I cried. I didn't think it is so possible for a person to cry so much.' (Sharron Frood interview with participant 8, Nelson Mandela Bay, July 2006)

The following statement by the AIDS orphans demonstrates how they experience feelings of **neglect**:

> 'The worst time to me was when I was sleeping in a Rainbow Chicken cupboard in Njoli Square where they keep the crates for chicken. I was cold and hungry and dirty. No one cared for me I was neglected by everyone even the people who pass [sic] me by on the street.' (Sharron Frood interview with participant 8, Nelson Mandela Bay, July 2006)

The feelings the participants experienced that can be categorised as '**mad**' feelings, were feelings of anger and rejection.

Anger is a very powerful emotion. It is experienced when a person is 'extremely displeased, irritated, frustrated or enraged by injustice of some sort; it is to experience animosity towards, resentment, or to have a bad temper towards another person or object' (Roger's Thesaurus 2005).

> 'I became so angry when I had become an orphan, I hated it. I hated being called 'orphan'. It was like a burning feeling in me and I all I wanted to do was to hit people. One day I was walking and I just kicked a stone all the way home. It made me to feel better.' (Sharron Frood interview with participant 1, Nelson Mandela Bay, May 2006)

All the participants experienced anger on becoming AIDS orphans. They stated that at times the angry feelings even made them irrational and that before the death of their parent or loved one they had been 'good children'.

To be rejected is to 'be put aside, to be sent back, to be unaccepted, to be used up and cast aside, to be unwanted, to lack value, to be imperfect and to be forsaken' (Oxford Advanced Learners Dictionary 2005). All the participants experienced feeling **rejected** by their extended families, community members and friends:

> 'No-one wants us anymore. We are like rubbish which blows around. We go here and there but no one wants us. We are like a dirty person who is made to be outside and we want to be loved but we are rejected. It is true no-one can love you like your mother.' [Sharron Frood interview with participant 2, Nelson Mandela Bay, May 2006)

The next feeling presented will be the '**scared'** group, and this includes feeling overwhelmed, fearful, uncertain and suicidal.

The AIDS orphans described feeling **overwhelmed** by their life circumstances because they became AIDS orphans and they said that they were bewildered, shocked, and completely overwhelmed by the enormity of their completely new reality as AIDS orphans. The following quotations encapsulate the feelings experienced in this regard:

> 'After my mother died I was overwhelmed because every day was difficult to me. I didn't know where to get food, how to wash my clothes and how to cook.' (Sharron Frood interview with participant 7, Nelson Mandela Bay, July 2006)

> 'After the funeral of my mother and everyone went I was just alone. I didn't know what to do so I just sat on my bed and I cry [sic]. I was like under a waterfall of bad things that just kept falling on my head.' (Sharron Frood interview with participant 4, Nelson Mandela Bay, June 2006)

Fear is an emotion caused by impending danger, evil, alarm or dread. It causes a living being to shrink back and to become anxious of something or of a situation. To be afraid is to be full of misgivings, mistrust or hesitation towards a person. It is to experience a nervous flutter, quivering or shaking because of a situation, or to experience despondency and despair (Roger's Thesaurus 2005). Following the death of their loved one, the orphans experienced extreme fear. The following excerpts from their interviews testify to this:

> 'When I came home with my sisters from my father's funeral I was afraid. I knew that my life would change to be hard now. I was afraid because there was no one to take care of us.' (Sharron Frood interview with participant 8, Nelson Mandela Bay, July 2006)

> 'When my father did die I was all alone in the home. I was very afraid at night because the house is not secure. I was afraid that someone will come in and rape and kill me.' (Sharron Frood interview with participant 4, Nelson Mandela Bay, June 2006)

The participants were all **uncertain** after the death of their loved one, because their lives as they knew it had changed and they became very unsure about the future and felt scared:

> 'When I thought about the future I was unsure of what would happen to me. Everything changed; I was now alone and I had no money and no job and no one to take care of me.' (Sharron Frood interview with participant 5, Nelson Mandela Bay, June 2006)

> 'I was afraid because I was not sure if I can continue my studies. I didn't know who will buy school uniform for me or pay my school fees.' (Sharron Frood interview with participant 3, Nelson Mandela Bay, June 2006)

Literature highlights the fact that orphans need a secure and loving environment after the loss of their loved ones. Orphans who are cared for, suffer less psychological distress caused by uncertainty and fear, than those left to fend for themselves (Wild 2001).

All the participants expressed a desire to die. Their lives had become void of all hope and they were full of pain. Harter (1998) contends that 'low self esteem in conjunction with depression and hopelessness seems to be the precursor of suicidal behaviour'. The participants all expressed their death ideation and **suicidal** feelings as follows:

> 'After the death of my mother I just wanted to die. The pain in my heart was too bad and I didn't want to live.' (Sharron Frood interview with participant 2, Nelson Mandela Bay, May 2006)

> 'Many times I wanted to kill myself after my mother pass [sic] away. One day I go the garage to kill myself but I just sat there. I couldn't do it.' (Sharron Frood interview with participant 1, Nelson Mandela Bay, May 2006)

The final feeling group presented is the **'glad'** group. The researcher would like to highlight that the **glad** feelings the

AIDS orphans experienced, all resulted from an intervention. The interventions the AIDS orphans referred to were, for example, when a neighbour brought them something to eat, when they were included in a game of soccer, when a relative paid their school fees, or when a friend gave clothes to them. One of the orphans commented:

> 'One day I was at school after the death of my mother. My friends went to the playground to eat their lunch. I went with them. We sat down and they shared their lunch with me. This gives me a hope that I can make it because they were kind to me.' (Sharron Frood interview with participant 2, Nelson Mandela Bay, May 2006)

This group will be presented in the next section.

Theme 2: AIDS orphans rediscovered hope to go on living

The AIDS orphans in this study regained hope to continue living when the extended family, their friends, boyfriends or girlfriends and community members started to reach out and help them. It was as if help extended to them awoke '**glad**' emotions in them:

> 'The morning after my mother's funeral a neighbour came to my home and brought me food. This gave me hope and made me to be happy because he was kind to me.' (Sharron Frood interview with participant 4, Nelson Mandela Bay, June 2006)

> 'My friend's mother come to me after the death of my father and that make me to be glad because now I am having clean trousers to wear. This made me to feel loved and I was glad.' (Sharron Frood interview with participant 3, Nelson Mandela Bay June, 2006)

The orphans clung to life. Some had contemplated suicide in the depths of their anguish and endured suffering because of the loss of their loved one. Yet they were still attending school, finding food, wearing clothes and speaking about the future. So what is hope? 'It is a concept which seems to have such a vital role in our lives, yet remains elusive to define even after years of inquiry' (Cutcliffe & McKenna 2005).

Hope has to do with expectation and desire. It is a platform that gives rise to security and reassurance. It is optimistic and full of promise. It is good and it lifts the spirits of a person. Hope encourages a heart to be glad (Roger's Thesaurus 2005).

The participants rediscovered hope through relationships, education, belonging to community groups and partaking in sport activities, to continue living. These 'pillars of hope' will now be presented as sub-themes.

Sub-theme 2.1 AIDS orphans rely upon relationships with friends, relatives and God to re-establish hope

All of the participants relied upon relationships to restore hope. Hope initially seemed fragile because the orphans found it difficult to accept and trust the help offered to them through their relationships with friends. The researcher would like to highlight that these relationships, no matter how tenuous, restored hope through the demonstration of care through practical giving. Friends and boyfriends or girlfriends reached out to the participants and gave food, shelter, clothing, kindness and a sense of belonging and love:

> 'My friend at school could see I was struggling. So he came to get me to go jogging with him every night. It was good to run. This gave me a good feeling that I had a future.' (Sharron Frood interview with participant 7, Nelson mandela bay, July 2006)

> 'I do like it when my boyfriend did tell me that he does love me. This does make me to have a hope that one day I will get married and have a home and a family. That is my dream and does make me to have hope in my heart.' (Sharron Frood interview with participant 8, Nelson Mandela Bay, July 2006)

The orphans experienced a paradox in their relationships with their extended families following the death of their loved one. In one incident, the extended family came to the home of the orphan and took household items after the death of the parent or loved one and failed to provide adequate support. In another incident, the extended family members offered help in the form of practical support, which benefited the AIDS orphan and helped him or her to regain hope:

> 'If my grandmother's sister didn't stay to take care of us after the death of my grandmother I don't know what we would have done. We had no money and we had no food. My grandmother's sister does use her pension to take care of us. She cares for us and I have a hope for the future.' (Sharron Frood interview with participant 8, Nelson Mandela Bay, July 2006)

> 'My cousin's sister came and brought me some clothes at Christmas time. Our clothes were old by that time and I did have a hope that I can go to church again because I do have nice clothes to wear. That made me to look to the future that it will get better for me and my brother and sisters.' (Sharron Frood interview with participant 6, Nelson Mandela Bay, June 2006)

Foster highlights:

> The extended family is like a net, which catches family members in need. This net, however, is stretched to capacity across the continent of Africa and orphans in particular have been left to care for themselves in child-headed households. It is the emergence of these child-headed households that demonstrates a breakdown in extended family capacity to care for orphans. (Foster 2002)

The researcher would like to highlight that, in most instances, following the death of their parents or loved ones, the AIDS orphans mostly experienced negative emotions. The feelings of hope that they initially experienced were short-lived and related to an intervention. The acts of kindness they experienced, however, did assist in restoring hope to them although it was fragile and short-lived.

All the participants referred to the way their relationship with God and prayer consoled them. They call on God in their distress and many were searching for the truth about God and seeking comfort and hope:

> 'I can say that I have a Bible by my bed and I do read it every night and I do pray to Jesus. I know He does hear me because I do always sleep nice afterwards. God gives me hope and strength.' (Sharron Frood interview with participant 8, Kwazakhele Township, July 2006)

> 'Without my prayer, I would give up. I know God does listen, and a grandmother in the community does pray for me every day. This does make me to have a hope for the future.' (Sharron Frood interview with participant 1, Nelson Mandela Bay, May 2006)

Sub-theme 2.2: The AIDS orphans re-established hope through education, by belonging to community groups and by engaging in sport activities

All the participants stressed the importance of their education. They enjoyed the school environment because they were not treated differently from other students, something they all appreciated. All the orphans in this study were motivated to learn, and keen to show their schoolwork to the researcher during the interviews. They all spoke about becoming doctors, lawyers, engineers, teachers and social workers. Their dreams of a future were still very much alive, and, fuelled by the opportunity, they have to learn and do well in school tests and gain recognition from their teachers.

When all other aspects of their environment had changed, school was the only place that remained constant: a place of learning, challenge and relative safety. It was familiar and relatively secure so that they all enjoyed focussing on their studies. It seemed that their studies were a kind of anchor for the future. The literature highlights that 'Education is the hope of children who are orphans because it keeps them focussed on the future' (Reed 2003). Bennell adds:

> The school environment is the friendliest of all the environments that orphans embrace, and that is why they attend school. They go to school because they aren't different there; they are simply children who need a good education to equip them for the future. (Bennell 2005)

With regard to education as a source of re-establishing hope, the participants had the following to say:

> 'When I am at school I am like everyone else. I do my studies and I am always talking about the future. This is good to me because I like to learn. Education is power and when I leave school I want to be social worker so I can help people who are suffering, like me.' [Sharron Frood interview with participant 8, Nelson Mandela Bay, July 2006]

> 'Education helps me to forget my problems. When I am at school, I am just learning. My best is History; I love History. I have no problems when I am at school just learning. I am determined to get a good job so I must learn. That is my focus.' (Sharron Frood interview with participant 1, Nelson Mandela Bay, May 2006)

The orphans involved in this study were glad to talk about the community groups to which they belonged and their activities within these groups. Inclusion in community groups helped the orphans to forget their problems and gave them a place to belong. They all enjoyed the groups they were involved in and felt strengthened emotionally by their involvement in the community activities they pursued. The following comments by the participants demonstrate how they felt about their community groups:

> 'I go every Saturday to my special Bible class. We are 10 in this class. We do study and we do learn and discuss things relating to the word of God there. I love my group because we all share and I do trust them. It's good to belong there. I am strong because of that group. Last year we go on a camp together. It was too much fun. I love my friends in this group and they do love me too. We talk about the future in this group and that does make us all to have a hope.' (Sharron Frood interview with participant 4, Nelson Mandela Bay, June 2006)

> 'One of the ladies in my community is having a community sewing project. I do go there to be with them. They are like mothers and they do teach me how to make things like mats and clothes. I do like them too much. They do give me help when I do have a problem and that does make me to have a hope. It's a good place to me I belong there and that does make me to feel good in my heart.' (Sharron Frood interview with participant 8, Nelson Mandela Bay, July 2006)

The participants stated that they loved playing games, enjoyed being part of a team and that they loved to win. They also said that participation in sport in the community gave them a sense of belonging and enabled them to be fully involved in an activity without thinking about their problems:

> 'When I play soccer it is like I am free that I can be anything. We are champions in the community. We win everything we play and that makes me to feel glad. Even if we lose I don't mind as long as it's a good game.' (Sharron Frood interview with participant 7, Nelson Mandela Bay, July 2006)

> 'I am playing hockey at my school. I like to be in a team. I feel like I do belong there. I am important to my team and they are important to me. It makes me to be glad. They encourage me and that does make me to be strong in my heart.' (Sharron Frood interview with participant 2, Nelson Mandela Bay, May 2006)

Hanrahan (2005) is of the opinion that the orphans in his study who were involved in a sports programme developed by a sports psychology department in Brisbane in Australia, had better global self-worth after the project, and they also experienced an increase in perceived life satisfaction. 'Furthermore, sport activities for orphans help them to be more hopeful concerning their future' (Hanrahan 2005).

Limitations of the study

A limitation in this study was that interviews were only conducted with AIDS orphans in three townships. Further input from AIDS orphans in other townships could be of value.

Recommendations

In the light of the research findings, the following recommendations were made for nursing practice, nursing education and research.

Nursing Practice

It is recommended that the stories of AIDS orphans living in a township should be made available through publications and workshops to all PHCNs in local health and government departments, who are involved in planning initiatives to assist AIDS orphans living in a township, and rendering services to such client systems.

Primary health-care nurses should facilitate the management of support groups for AIDS orphans; therefore, they should receive the necessary professional development training with regard to the co-ordination and facilitation of support groups.

The planning of care for potential AIDS orphans should be initiated on diagnosis of HIV infection in the parent or loved one who is caring for them. Through planning and support by way of the health and education structures, some of the devastation they experience on becoming AIDS orphans could be prevented. If parents who are dying of AIDS plan for their children who are to become orphans, AIDS orphans are less likely to be left without care and support when their parents die and less likely to become destitute. Therefore, PHCNs should help patients who attend the clinic for ARVs to plan for the care of their children who will become orphans on their death. Primary health-care nurses should be equipped to facilitate and co-ordinate a planned approach in response to AIDS orphans living in townships.

Nursing education

A course component about the lived experiences of AIDS orphans in a township can be presented to nursing students during the primary health-care module of their course to provide insight and to equip students to care for AIDS orphans living in a township. It is suggested that the subject of ‘AIDS and AIDS orphans’ should not be separated because of the health and social response required to care for these children.

Nursing research

It is recommended that similar studies be conducted by using the themes identified in this study to develop a questionnaire for a quantitative study to test the generality of these themes.

Conclusion

The main aim of the study on which this article reports, was to gain insight into the lived experiences of AIDS orphans in a township in order to understand their ‘life world’ as AIDS orphans. Information obtained could be disseminated also to those providing care to the orphans, so that they could use it as a basis when planning a care response to meet the unique needs of the orphans.

It is evident from the research findings that this study succeeded in achieving the research objectives because the children expressed devastating changes in their life circumstances as a result of becoming AIDS orphans, thus making valuable information accessible to all those involved in the care of AIDS orphans. The participants expressed a variety of experiences because of the absence of a parent or a loved one in the home. Such experiences included taking part in high-risk behaviour; the rediscovery of hope to go on living by engaging in activities such as education; belonging to community groups; and engaging in community sport activities.

In conclusion, the findings of this study are sufficient to be used as a foundation upon which primary health-care nurses (PHCNs) involved in the care of this interest group can initiate a care response for AIDS orphans, even though only participants from three townships were included in this study. Understanding the ‘life world’ of AIDS orphans who live in a township is vital before a care response is planned to meet their unique needs.

Acknowledgements

The authors would like to thank Jackie Venter for the editing of this manuscript, as well as thank the participants who shared their experiences willingly.

Competing interests

The authors declare that they have no financial or personal relationship(s), which may have influenced them inappropriately in writing this paper.

Authors’ contributions

S.F. (Gogo Trust) conducted the research and drafted the manuscript. D.v.R. (Nelson Mandela Metropolitan University) and E.J.R. (Nelson Mandela Metropolitan University) corrected and refined the manuscript, and were the research supervisor and co-supervisor, respectively.

References

Babbie, E. & Mouton, J., 2002, *The practice of social research,* Oxford University Press, Cape Town.

Bennell, P., 2005, ‘The Impact of the AIDS Epidemic on the Schooling of Orphans and other Directly Affected Children in Sub-Saharan Africa’, *The Journal of Developmental Studies* 41(3), 467–488. http://dx.doi.org/10.1080/0022038042000313336

Burns, N. and Grove, S. K., 2009, *The practice of nursing research. Appraisal, synthesis and generation of evidence*, 6th edn., Saunders Elsevier, United States of America.

Butler, A., 2004, *Contemporary South Africa,* Palgrave Macmillan, New York.

Creswell, J.W., 1994, *Research design: Qualitative and quantitative approaches*, Sage, London.

Creswell, J.W., 2003, *Research design: Qualitative, quantitative and mixed methods approaches*, 2nd edn., Sage, United States of America.

Cutcliffe, J.R. & McKenna, H.P. (eds.), 2005, *The essential concepts of nursing*, Elsevier Churchill Livingstone, New York.

De Boeck, F. & Honwana, A., 2005, *Children and youth in post-colonial Africa*, Blackwell, Oxford.

Denscombe, M., 2008, *The good research guide for small-scale social research projects,* 3rd edn., Open University Press, Finland.

Foster, G., 1997, ‘Orphans, Disease, HIV Infections and Treatment’, *AIDS Care* 9(1), 82–87. PMid:9155922

Foster, G., 1998, ‘Today’s Children: Challenges to Child Health Protection in Countries with Severe AIDS Epidemics’, *AIDS Care* 10(1), 17–23.

Foster, G., 2002, ‘Community Supports Orphan Families: AIDS and the Orphan Crisis’, *Recovery* 1(8), 7–9.

Guest, E., 2001, *Children of AIDS*, Pluto Press, London.

Hanrahan, S.J., 2005, ‘Using Psychological Skills Training from Sports Psychology to enhance the Life Satisfaction of Adolescent Mexican Orphans’, *Journal of Sports Psychology* 7(3), 1–7.

Harter, S., 1998, ‘Self and Identity Development’, *Journal of Adolescent Health Care* 9, 352–355.

Ivey, E.A., 1999, *Interviewing and counselling*, 4th edn., Brooks/Cole, Pacific Grove, California.

Jacobs, M., Shung-King, M. & Smith, C. (eds.), 2005, *South African child gauge,* Children’s Institute, University of Cape Town, Cape Tzown.

Jolley, J., 2010, *Introducing research and evidence-based practice for nurses*, Pearson Education Limited, Great Britain.

Loening-Voysey, H., 2002, 'Community Supports Orphan Families: Caring for Vulnerable Children', *Debate* 9(1), 105–107.

Matshalaga, N.R., 2002, *Mass orphanhood in the era of HIV/AIDS*, viewed 28 November 2011, from EBSCOhost: Academic Search Premier, Item: AN60004754. http://web.ebscohost.com/ehost/resultsadvanced?sid=86f025ea-be7e-40cb-83c5-2d9dd9e01dac%40sessionmgr114&vid=5&hid=8&bquery=(TI+(%26quot%3bmass+orphanhood+in+the+era+of+hiv%2faids%26quot%3b))&bdata=JmRiPWE5aCZ0eXBlPTEmc2l0ZT1laG9zdC1saXZl

Meyer, J., 2005, *Approval addiction*, Warner Books Edition, New York.

Mogotlane, S.M., Chauke, M.A., Van Rensburg, G.H., Human, S.P. & Kganakga, C.M., 2010, 'A Situational Analysis of Child-headed Households in South Africa', *Curationis* 33(3), 24–32. PMid:21428236

Oxford Advanced Learner's Dictionary, 7th edn., 2005, Oxford University Press, Oxford.

Polit, D.F. & Hungler, B.P., 1999, *Essentials of nursing research: Methods, appraisal and utilisation,* 4th edn., Lippincott Company, Philadelphia.

Reed, L., 2003, 'Education is our Hope', *Faces* 20(1), 34–37.

Roger's Thesaurus, 5th edn., 2005, Oxford University Press, Clarendon.

Streubert, H.J. & Carpenter, D.R., 1995, *Qualitative research in nursing: Advancing the humanistic imperative,* J.B. Lippincott, Philadelphia.

UNAIDS, 2008, *Report on the global AIDS epidemic status*, UNAIDS, Geneva.

UNAIDS, 2009, *AIDS epidemic update, November 2009,* viewed 12 April 2010, from http://www.unaids.org/en/KnowledgeCentre/HIVData/EpiUpdate/EpiUpdArchive/2009/default.asp

UNICEF, 2006, *Africa's orphaned generations. Children affected by AIDS*, UNICEF, New York.

Welman, J.C., Kruger, F. & Mitchell, B. 2010, *Research methodology*, 3rd edn., Oxford University Press, Cape Town.

Wild, L., 2001, 'The Psychosocial Adjustment of Children Orphaned by AIDS', *Southern African Journal of Child and Adolescent Mental Health* 13(1), 3–20.